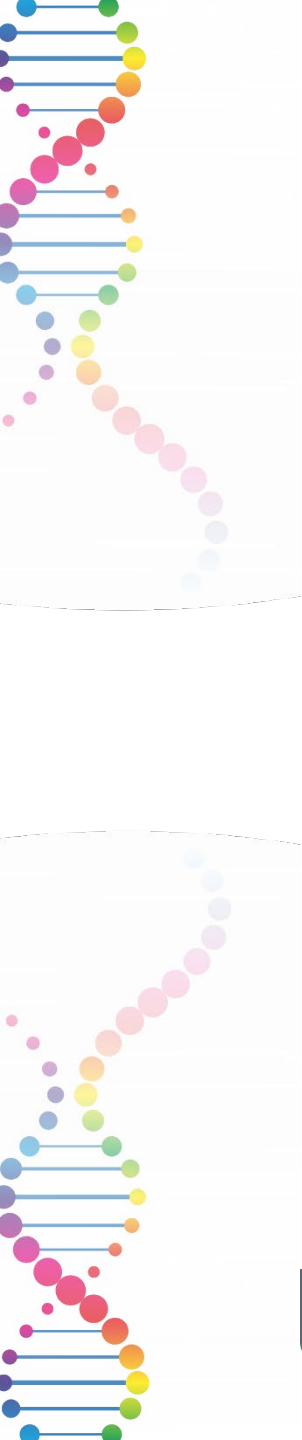


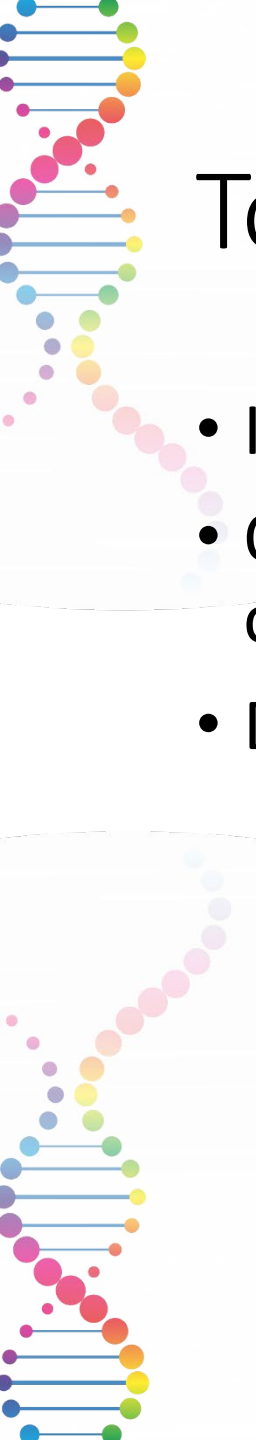


Bridging research and practice: examples from EXCEED

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Today's session

- Introduction to EXCEED and the data available
- Overview of current research on local trends in illness burden and complexity and how these interact with health inequalities
- Discussion on opportunities, barriers and priorities for local research



(Extended Cohort for E-Health, Environment and DNA)

is a population-based study
of over 11,000 participants

Launched in 2013

Recruitment is ongoing with a
focus on boosting participation
from underrepresented ethnic
groups



Sign up is via
the **E×CEED**
website

exceed.org.uk



Average age of
participants is

67.7
YEARS



56%
of the cohort are female

Some common long-term conditions

37%

High blood pressure



14%

Asthma



12%

Diabetes



>26%

Mental health
conditions

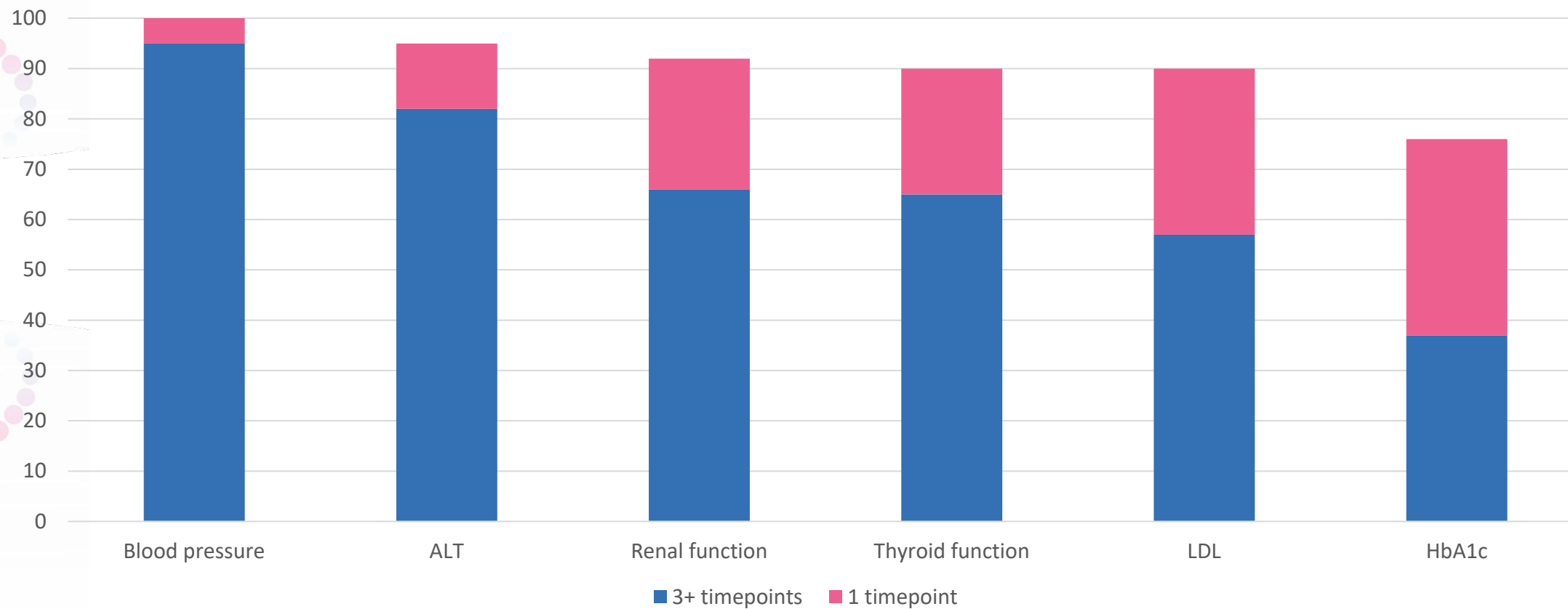


6%

Cancer



Longitudinal primary care data





Wider data

- Baseline: smoking & alcohol history, lung function, height, weight
- Follow-up: COVID-19 symptoms, vaccination, mental health, social and economic impacts, serology
- Health record linkage: primary care, secondary care
- Environmental data: noise, air pollution, greenspace, temperature
- Biological samples:
 - 8528 with genetic data
 - 1979 with proteomics, 1524 with metabolomics, 877 with glycomics



Research examples: Overview

- 77 projects approved to use EXCEED data so far
- 28 publications to date
- Open to researchers in Leicester and beyond
- Very broad range of conditions, risk factors and body systems studied using linked healthcare data
- Two published examples to illustrate some of this breadth



Research examples

(1) Treatment-resistant depression

[nature](#) > [molecular psychiatry](#) > [articles](#) > article

Article | [Open access](#) | Published: 22 March 2021

Genetic and clinical characteristics of treatment-resistant depression using primary care records in two UK cohorts

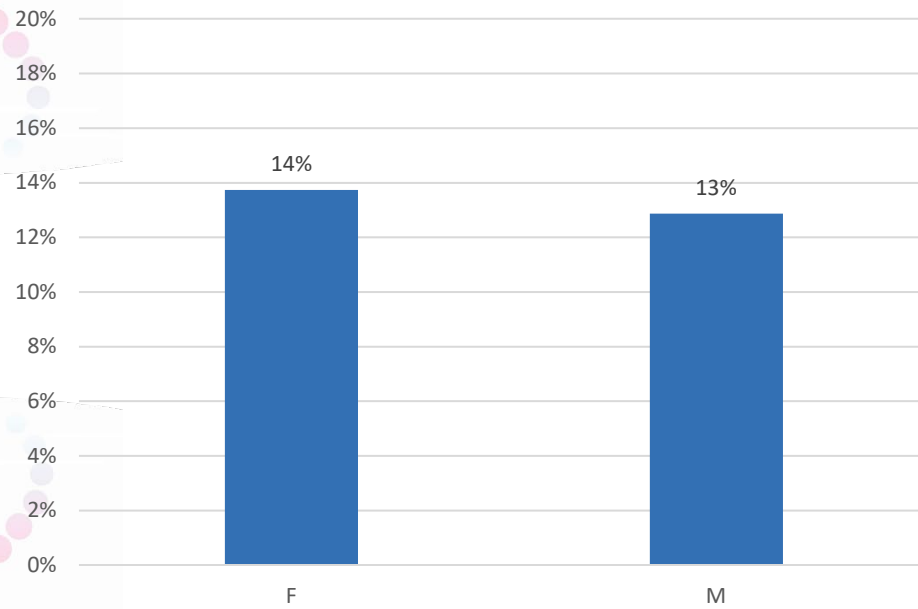
[Chiara Fabbri](#), [Saskia P. Hagenaars](#), [Catherine John](#), [Alexander T. Williams](#), [Nick Shrine](#), [Louise Moles](#), [Ken B. Hanscombe](#), [Alessandro Serretti](#), [David J. Shepherd](#), [Robert C. Free](#), [Louise V. Wain](#), [Martin D. Tobin](#) & [Cathryn M. Lewis](#) 

[Molecular Psychiatry](#) **26**, 3363–3373 (2021) | [Cite this article](#)

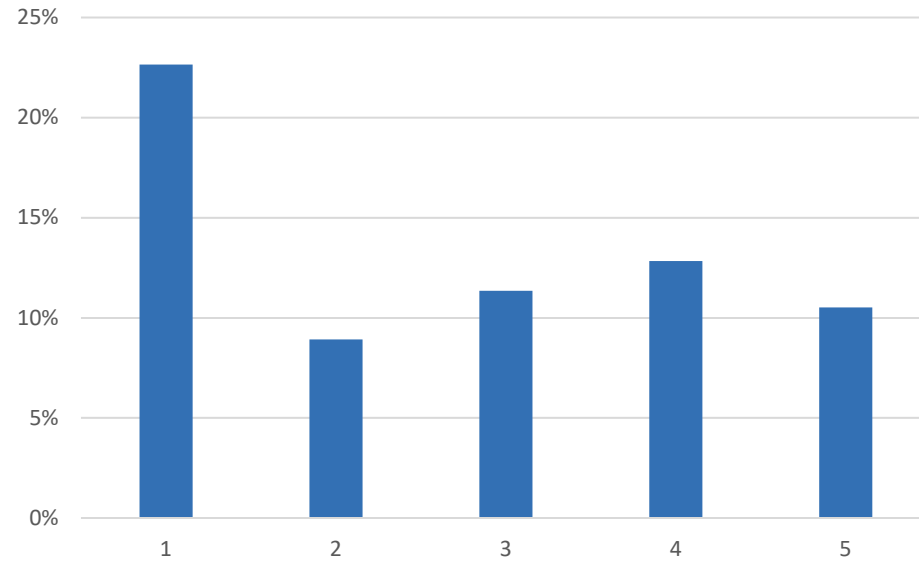
Research examples

(1) Treatment-resistant depression

% TRD by sex



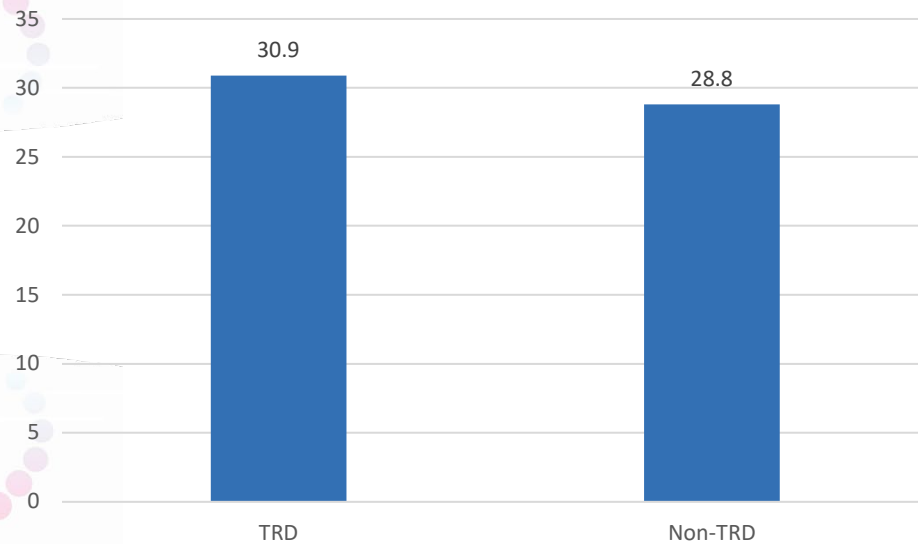
% TRD by quintile of deprivation
(1 = most deprived)



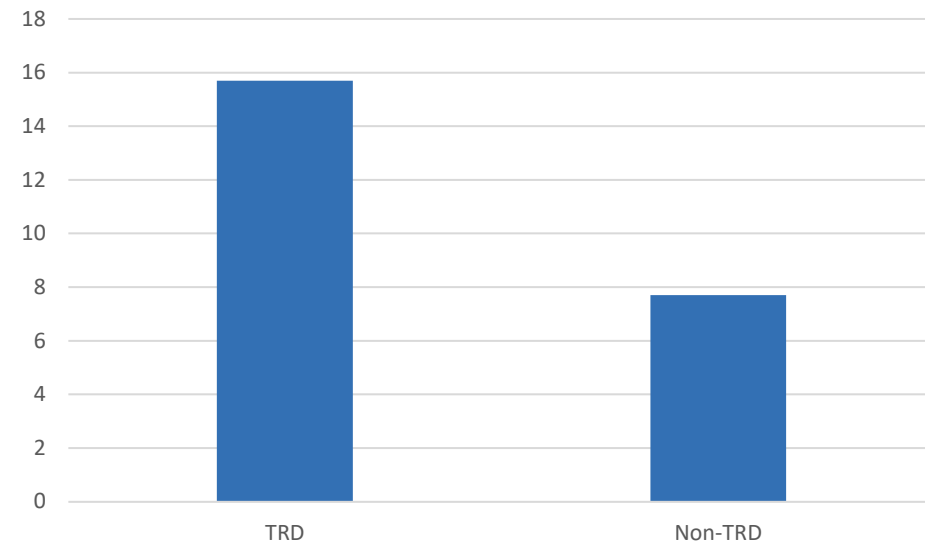
Research examples

(1) Treatment-resistant depression

BMI



% with diabetes diagnosis



Research examples

(2) ACE-inhibitor cough



There are shared biological mechanisms and genetic overlap between ACE inhibitor-induced cough and chronic dry cough.



Identified genetic variants which increase the risk of experiencing cough as a side-effect of ACE inhibitors.



Many variants implicate genes which encode proteins with important neurological functions.



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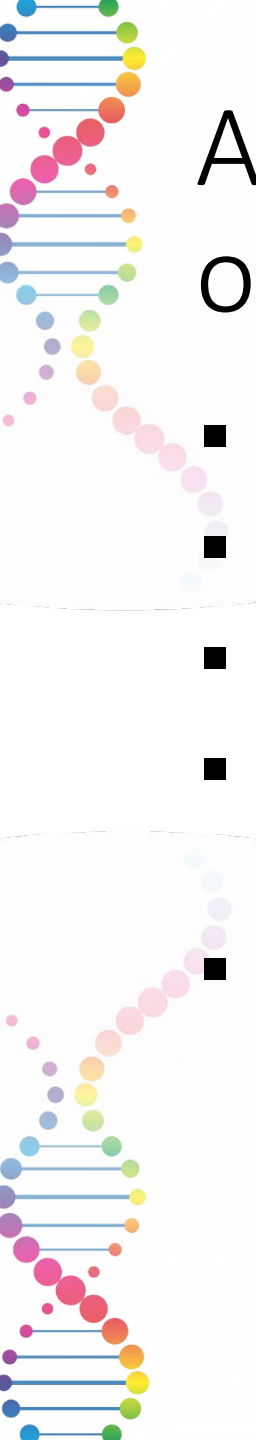
University Hospitals of Leicester
NHS Trust



Research examples

(2) ACE-inhibitor cough

- We can reliably identify ACE-inhibitor cough from primary care records by identifying switches from an ACE-inhibitor to an angiotensin receptor blocker
- In EXCEED, women were ~1.4x more likely to experience ACE-i cough than men



A challenge for LLR: trends and determinants of illness burden and complexity

- Over half the global population has 2+ long-term health conditions
- More than half of NHS costs in primary & secondary care
- Unequally and unfairly impacts the most disadvantaged
- Treatment often manages symptoms rather than fixing the underlying cause
- Key priority for research locally and nationally



A challenge for LLR: trends and determinants of illness burden and complexity

- Proportion of population in LLR ICB with high illness burden has increased sharply, approximately doubling from 2018 to 2024
- This is replicated in Frimley ICB where the proportion increased ~4x
- The two areas have different populations and different software used in primary care
- In LLR the increase is more marked in middle-aged and older people
- **Research question: which diagnoses are driving this change and what are the possible causes?**



EXCEED and illness burden

- Very similar trend is seen in the EXCEED cohort, even when taking into account ageing of the cohort
- Increase is again sharpest in middle aged/older people
- Similar patterns are seen when different definitions of severity/complexity/frailty are used
- Trends not markedly different between broad ethnicity groups
- Deprivation is strongly correlated with illness burden at baseline but **even more strongly correlated with the trend over time, i.e.** inequalities are increasing



Discussion

- 1) Does the data on illness burden/complexity reflect (or not) your local experience, practice or research?
- 2) Based on your own experience, practice, or research, what other factors would you consider investigating to better understand trends in illness burden/complexity?
- 3) What are the local health inequalities, trends or challenges where research in local cohorts like EXCEED could help provide insight?



Next steps

- Formal age-standardised analyses
- Contributions of individual conditions/groups of conditions
- Associations with potential risk factors
- Sensitivity analyses to look for differences by service/system factors

Acknowledgements

EXCEED team members past & present...



...and most importantly – the participants.

We need your help!



Extended cohort for e-health, environment and DNA

EXCEED is a research study that wants to understand how your DNA, lifestyle and daily habits influence your health

Over
18 years
old



Leicester,
Leicestershire
or Rutland



Asian,
Black, Arab,
or mixed ethnic
background

Together we can make a healthier future for all



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We need your help!

- We would love to hear from you!
- Please get in touch with:
 - Possibilities for further building engagement with communities
 - Local policy or service challenges where local research could help
 - Anything else you'd like to get involved in!
- Email: exceed@leicester.ac.uk